

- Introduction
- What is fatigue?
- Recognising fatigue
- What causes fatigue
- Managing fatigue

Fatigue in MSA

Introduction

There is very little written about fatigue in multiple system atrophy (MSA) but we do know that it is a symptom that affects a lot of people living with MSA. It is therefore important to look at ways of managing fatigue in MSA. This short guide has been put together to help people with MSA identify and manage difficulties with fatigue. Occupational therapists are good at assessing fatigue and working with all the multi-disciplinary team (MDT) to help manage the problems.

What is fatigue?

Fatigue can present itself as an overwhelming sense of tiredness, lack of energy and feeling of exhaustion and is different from the sense of tiredness people without MSA experience. Fatigue can have a significant effect on a person's ability to deal with day to day activities. Fatigue can also affect the person's cognitive ability, speech, psychological wellbeing, relationships and mood.

Recognising fatigue

If you feel you may be affected by fatigue, a useful way to check is to see if you have six or more of the symptoms:

- Diminished energy, or increased need to rest, disproportionate to any recent change in activity level
- Complains of general weakness or limb heaviness
- Diminished concentration or attention
- Decreased motivation or interest to engage in usual activity
- Insomnia (little sleep) or hypersomnia (excessive sleep)
- Experience of sleep as un-refreshing or un-restorative

Fatigue in MSA

- It feels like a real effort to get going, or get on with a task
- Overwhelming emotions around feeling fatigued
- The feeling of problems with short term memory
- Post-exertion malaise (a general sense of feeling out-of-sorts) lasting several hours.

What causes fatigue?

The causes of fatigue in MSA can be endless and it is quite often listed as a symptom for most diseases and conditions. We don't know yet what causes it in MSA but it is likely to be a number of factors related to your other symptoms. These fall into four general areas: physical, emotional, environmental and biological.

Physical aspects

Deconditioning . having MSA means a greater effort is needed to be mobile, this can lead to deconditioning of the muscles and the cardiovascular system, which in turn can lead to fatigue. It is important you talk to your physiotherapist about this.

Lower blood pressure . may well cause fatigue and should be checked and treated where possible. The Trust has a fact sheet about blood pressure and dealing with postural hypotension.

Sleep disturbance . sleep problems are common in MSA and addressing these can help sleep which can in turn help reduce fatigue. Talk to your GP or specialist about managing pain, anxiety or urinary urgency at night.

Extra effort . this is the increased energy expenditure due to the extra effort needed to do everyday tasks e.g. washing, dressing, and getting out of a chair.

Emotional aspects

Low Mood /Depression . this should be assessed for and treated. Low mood can lead to less motivation to be active, which can in turn lead to fatigue. It is important you talk to the GP or specialist about this.

Environmental aspects

Lighting . poor lighting causes increased visual effort which can cause fatigue.

Temperature . extreme temperatures can cause fatigue

Noise . too much auditory stimulation can cause fatigue

Biological aspects

Medications . it is important to monitor if any changes in medication make fatigue worse. Make a note of any medication changes and any changes in fatigue and discuss with the GP or specialist.

Infection . any infection can make MSA symptoms worse and so it is important to be aware of the risk of infection and treat infection promptly. It is important to be aware that the lack of a high temperature does not rule out the possibility of infection.

Fatigue in MSA

Managing fatigue

If you are suffering from loss of energy, exhaustion or overwhelming tiredness then ask your Occupational Therapist to assess your fatigue and help you develop a management plan. They will also need to liaise with other members of the care team. You might want to consider the following areas:

Exercise and nutrition

A good balanced diet and as much exercise as you are able may help combat fatigue. You should speak to a dietician about your diet and a physiotherapist about safe, beneficial, exercises. And remember to drink plenty of water, this is so important for many aspects of MSA and is known to help fight fatigue.

Rest and relaxation

Getting a good night's sleep is so important but can be difficult. You can promote your chances of a good night's sleep by good sleep hygiene and addressing issues of anxiety, pain and night frequency of urine, the MSA Nurses will be able to offer advice on these. It could also help to learn some effective relaxation techniques

Planning and delegating

It is important that you pace activities and allow plenty of time for rest and recovery. Don't be afraid to accept help or delegate things to others, either family or friends or even outside agencies. It is difficult to ask for support but the people around you will be happy to help. Planning a weekly diary balancing activities and allowing quiet days and periods will help manage your activity and a good tip is to keep a fatigue diary. Once you know your own levels of activity you can develop a realistic weekly plan and it will help you prioritise important events and activities, so the things that matter most, you are still able to do.

Mood and anxiety

It is easier said than done but try avoiding stress, identify the things that cause stress and work out ways to reduce the problem; an occupational therapist will help you here. If the fatigue is caused by low mood then it might be worth considering therapy or medication, you should talk to your GP about this.

Medication

If you have found that medication could be a cause of your fatigue then discuss this with your GP or specialist.

Environmental changes

If you have sensitivity to heat and you feel it is affecting your fatigue levels then avoiding extremes of temperature will help. This may sound obvious but we all have a tendency to put up with what we see as minor inconveniences but these all add up. Getting conditions right will give you the best chance to combat fatigue. Adaptations or alterations to your home environment may also help reduce the impact of fatigue and some aids may be available depending on your local authorities resources.

You may be able to get help with a short term wheelchair loan or apply for blue badge scheme especially if you are unable to stand for too long or get tired walking long distance. These facilities may also be available to you if you are planning a short holiday or day trip. It is important to speak with your Occupational Therapist who can arrange this for you.

Further support

If you develop or suffer with acute fatigue, you must discuss this with your GP or Specialist Nurse as your symptom of fatigue may be unrelated to MSA for example you may suffer with 'anaemia' (low level of iron in your blood) or simply an infection, which are all treatable.

Key points to remember

- If you are feeling overwhelmingly tired, have a loss of energy or feel exhausted you may be suffering from fatigue
- If you feel you are suffering from fatigue then consult your occupational therapist
- Working with your care team you can develop a plan that will help you manage the issue more effectively

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